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COMPLUTENSE

## [en] Protons for Jehovah's Witnesses? How press coverage of Ashya King's case brought proton beam therapy to the public sphere<sup>1</sup>

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**Abstract.** The case of Ashya King, the child brain tumour patient whose parents took from a British hospital so he could be treated with Proton Beam Therapy (PBT) abroad, contributed to popularize that technology among a general audience. Through the content analysis of British and Spanish press coverage ( $N=329$ ), our research shows that proton therapy enjoyed scarce coverage in the analysed media before Ashya King's case. His story, magnified due to the fact that his parents were Jehovah's witnesses was a cause both for public concern and media sensationalism. We show that the case brought PBT into the public sphere and, consequently, contributed to create a demand for facilities that offered this therapy. This case provides new data about how technology and medical controversy reaches different audiences: while the sphere of experts keeps debating about the benefits of the therapy, the public sphere has already decided to adopt it.

**Keywords:** Sensationalism; public sphere; controversies; empowerment; proton therapy; experts, journalism.

## ¿Padres secuestradores o empoderados? Cómo la cobertura mediática del caso Ashya King difundió la terapia de protones en la esfera pública

**Resumen.** El caso de Ashya King, el niño con un tumor cerebral cuyos padres sacaron de un hospital británico para que pudiera ser tratado con terapia de protones (TP) en el extranjero, contribuyó a popularizar esta tecnología entre el público. Mediante un análisis de contenido de la cobertura en diversos periódicos británicos y españoles ( $N=329$ ), nuestro estudio muestra que la TP apenas tuvo cobertura antes del caso de Ashya King. Su historia, magnificada por el hecho de que sus padres eran Testigos de Jehová, despertó preocupación social y sensacionalismo mediático. Este caso llevó la TP a la esfera pública y contribuyó a crear una demanda de instalaciones que ofrecieran esta terapia. El caso proporciona nueva información sobre cómo la tecnología y las controversias médicas llegan a diferentes audiencias: mientras que la esfera de expertos sigue debatiendo los posibles beneficios de la terapia, la esfera pública ya ha decidido adoptarla.

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**Palabras clave:** Sensacionalismo; esfera pública; controversias; empoderamiento; terapia de protones; expertos; periodismo.

**Summary.** 1. Introduction; 1.1. Patients raise their voices on the public digital sphere; 1.2. The purpose of research. 2. Methods. 3. Results; 3.1. General results; 3.2. Proton therapy before and after Ashya King's case; 3.3. Protons and religious beliefs; 3.4. Who explains proton beam therapy?; 3.5. Comparative by countries. 4. Discussion. 5. Conclusion. 6. References.

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## 1. Introduction

The case of the British boy Ashya King jumped to the headlines on August 28 2014. Little Ashya suffered a brain tumour and was taken from the Southampton General Hospital (United Kingdom) by his parents without medical consent, because they opposed the treatment protocol. Doctors warned the child's life was in danger so an international arrest warrant was issued. The fact that the parents were Jehovah's Witnesses got the media's instant attention. Jehovah's Witnesses are known for their absolute refusal of blood transfusions, even when the life of one of their members is at risk. When paternal refusal is based on religious beliefs, the court can justify compulsory medical treatment based on the avoidance of physical harm (Wooley, 2005). The family was found in Málaga (Spain) and the parents were arrested by Spanish police. Moments after the arrest, his older son published a video on YouTube which showed Ashya with this father, who explained that they just wanted to have proton beam therapy (not accessible in UK) instead of conventional radiotherapy proposed by British doctors.

Before the video on YouTube, parents were considered kidnappers by the press. After this video statement, broadcasted from a private sphere to the public one (Habermas, 1992), a clamour of public opinion began to call for the release of the parents so that they could be reunited with their child. On September 2, the Crown Prosecution Service discharged the arrest and the parents were finally released. Then, the whole family left Spain and flew to Prague, where the child was treated with proton therapy in a private centre. The National Health Service (NHS) finally paid the treatment. Months later, the NHS announced that the plan to build two proton therapy units in the United Kingdom, in London and Manchester, would finally be set in motion the summer of that year with a £250 million investment (National Health Service, 2015). Given that the treatment was not recommended by the medical team, was the NHS's decision to fund this treatment influenced by the great media coverage of Ashya's case? Did the fact that Ashya's parents were Jehovah's Witnesses help to increase this coverage? Did Ashya's case help to disseminate proton beam therapy?

Proton therapy is a radiation technique that uses protons instead of the photons used by conventional radiotherapy. This enables the maximum energy to be administered uniformly on the harmed tissue, without emitting radiation outside of it and, therefore, without affecting healthy tissue around it. These characteristics

make it a good choice for the treatment of tumours located next to structures such as the spinal cord, eyes and brain (Levin et al., 2005; Merchant, 2009). It is also important in the case of paediatric tumours, because the organs of these patients are still developing and are very sensitive to radiation (Rombi et al., 2014). That is the reason why some studies have defended the advantages of this therapy in maintaining organ function and reducing second tumours in the paediatric population (Childs et al., 2012; Hall, 2006). Nevertheless, the benefits of proton therapy still should be confirmed by new studies and clinical trials (Epstein, 2012; Merchant, 2013).

### **1.1. Patients raise their voices on the public digital sphere**

It is increasingly common for patients and their families to seek for and obtain information on the Internet, and that increasing access to information on diseases and treatments has modified the relationship between doctors and patients (Kivits, 2009; Richards, 2014). Although some studies indicate that the information patients find on the Internet contributes to improve the clinical encounter (Helft et al., 2003), there are also some reservations, particularly when the information obtained does not concur with the treatment protocol decided by the medical team (Imes et al., 2008). As happened in this case, some parents turn to the Internet to find information or advice, to read studies, and to learn more about the drugs their child will be or has been administered (Domínguez and Sapiña, 2015). Ashya's parents admitted to having looked for information about proton beam therapy on the Internet. With the generalized access to information about protocols, clinical trials and second opinions that came with the Internet, the therapeutic treatment takes a transnational dimension (Bell et al., 2015). In this case, the King family and the medical team did not reach an understanding, so the parents decided to act on their own and resort to a private hospital in Prague, where the boy could receive proton beam therapy instead of conventional radiotherapy.

### **1.2. The purpose of research**

The media and medical controversy around the case of the King family, both in the United Kingdom and in Spain (country where the family fled to after leaving the hospital and where the parents would be arrested), gave media relevance to a relatively unknown therapy. In other cases, due to the impact of different media figures, a therapy has been spread (Evans et al., 2014). The King family was not famous before their hospital journey, but they acquired media notoriety from the very first moment, when the international arrest warrant was issued and their Jehovah's Witnesses condition highlighted.

One of our hypotheses are that media interest increased when the parents' religion was brought up, and that this focus of attention helped to disseminate PBT in a way that highlighted its advantages and generated a demand for this medical equipment to be implemented in the UK.

Following this, we propose the following research questions:

RQ1: Was the media coverage of Ashya's case useful to disseminate the PBT for cancer treatment?

RQ2: Did the fact that the members of the family were Jehovah's Witnesses influence media coverage?

Trying to know if the newspapers' coverage was balanced, presenting every opinion, we also take in consideration this question:

RQ3: Who were the main actors involved in the media controversy: the parents, oncologists, physicists or public administrators? We also consider that the debate on PBT was more important in the UK than in Spain, so we compared media coverage in both countries.

RQ4: Was there a difference in the news coverage by English and Spanish newspapers? Which issues were highlighted in each country? This comparison will allow us to know how PBT was disseminated in both contexts and the reasons of possible differences between them.

## 2. Methods

We conducted a content analysis regarding Ashya King from August 29, 2014, when the media published the first piece of news on the child's disappearance, to March 24, 2015, the day after Ashya's family announced that the child was cancer-free.

The sample comes from twelve newspapers, six Spanish ones and six English ones. The Spanish newspapers were: *El País*, *El Mundo*, *La Vanguardia*, *El Periódico*, *ABC* and *La Razón*. We also studied six English newspapers: three broadsheets – *The Times*, *The Guardian*, *The Daily Telegraph* – and other three tabloids – *The Daily Mail*, *The Sun* and *The Daily Mirror*. The selection tries to cover newspapers with different ideologies and different target audiences.

Spanish data was collected through *mynews* and British data was collected through *Factiva*, both online academic newspaper databases. Three different keywords were used for the search: "Ashya King", but also "Aysha King", because the name was sometimes mistaken in press, and "proton beam therapy" ("terapia de protones" for Spanish searches). All information and opinion genres were included. The search with those terms yielded 247 pieces in Spanish newspapers and 360 in the British press. After screening (redundant news from different editions in the same newspaper were removed), 97 valid articles remained for the analysis in the Spanish sample and 232 in the English sample. In total, 329 pieces, from August 29, 2014 to March 24, 2015, were analysed.

In order to discover whether or not proton beam therapy was already well-known before the Ashya King case, we searched also for the keywords "protons" and "cancer" ("protones" and "cáncer" for Spanish searches) in any date before August 29, 2014, in the newspapers using the online archives of each of them, as well as in databases. In the Spanish press, we obtained 16 valid results with information about PBT before Ashya's King case. In the UK press, we obtained 33 valid results. In total, 49 other items were collected outside the sample dedicated to Ashya's case. These items allowed us to know the degree of interest towards PBT before the facts presented in this work took place.

All the articles were read and classified according the following codification: newspaper, date, title, genre, section, length and main purpose of the article,

whether it included information about therapy protons or not and which was the source responsible for explaining the technique. We also included some fields to analyse whether or not the articles highlighted the economic debate on proton therapy and whether or not the articles remarked on the parents being Jehovah's Witness. The codification was made by one of the researchers after a period of analysis and when a consensus of the categories was reached with the rest of team members. The categorisation of analysis units was verified with an intercoder test. Two other independent researchers coded 10 % of the sample, and the intercoder reliability was 0.74 and 0.71 respectively, which shows satisfactory agreement according to Cohen's Kappa coefficient in both cases.

All data was entered in IBM© SPSS© Statistics v22 software for Windows.

### 3. Results

#### 3.1. General results

In Spanish media coverage, conservative newspapers devoted more space to the King case than progressive ones. Thus, *La Razón* was the newspaper that devoted more space to the case, with 7.3 % of the news items in the sample. *La Vanguardia* and *ABC* followed with 6.7 % and 6.4% respectively, and *El Mundo* with 4.9 %. *El País* published 2.4 % of them and *El Periódico* was the one with the lowest coverage of the case, with only 1.8 %. Among the British newspapers, *The Daily Telegraph* (19.5 %) was the one that devoted more attention to the case, followed by *The Sun* (13.4 %), both conservative as well (Table 1). They are followed by *The Daily Mirror*, with 12.5 % of the sample, and *The Daily Mail* with 10.3 %. *The Times* (8.2 %) and *The Guardian* (6.7 %) occupy the last positions.

Table 1. Number of items analysed by newspaper.

Newspaper	Items N (%)
<i>El País</i>	8 (2.4 %)
<i>El Mundo</i>	16 (4.9 %)
<i>ABC</i>	21 (6.4 %)
<i>La Vanguardia</i>	22 (6.7 %)
<i>El Periódico</i>	6 (1.8 %)
<i>La Razón</i>	24 (7.3 %)
<i>The Times</i>	27 (8.2 %)
<i>The Guardian</i>	22 (6.7 %)
<i>The Telegraph</i>	64 (19.5 %)
<i>The Daily Mail</i>	34 (10.3 %)
<i>Daily Mirror</i>	41 (12.5 %)
<i>The Sun</i>	44 (13.4 %)

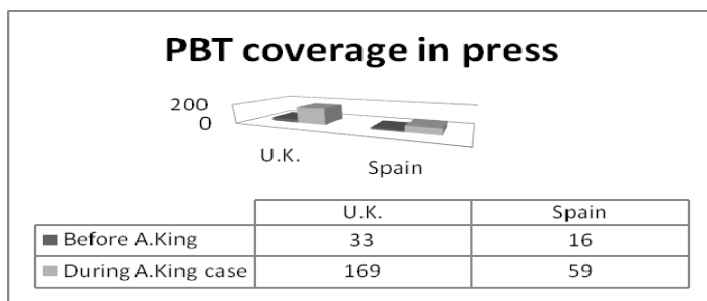
#### 3.2. Proton therapy before and after Ashya King's case

Ashya King's case marks a turning point in the public understanding of proton therapy. In previous years, there is almost no reference to proton therapy in the press:  $N=49$  for both, the Spanish ( $n=16$ ) and British ( $n=33$ ). In Spanish press, the first reference was published in *El Periódico* in 2003, in an opinion article written by a Professor of Physics of the University of Barcelona, who spoke about proton therapy as an option to treat cancer. In 2004, an interview in *El País* with a CERN researcher, highlighted the utility of designing particle accelerators to develop new cancer therapies. In 2006 and 2007, several pieces on the Institute for Medical Physics were published. It was a project to build a great facility to combine research and medical therapy, and was supposed to open for patients in 2012. In this case, one of the news items collected some disagreement among experts concerning such an expensive investment and whether or not it was justified, given the small number of patients who could benefit from it.

Regarding the British press, there were more references focused on proton therapy ( $N=33$ ) before the Ashya King case, especially from 2008, when the NHS started sending patients abroad to receive the treatment. Several newspapers published news about different cases of adult cancer patients or parents of children with cancer who explained their story. In these cases, although PBT is mentioned, the news focused on human interest rather than technology or other economic or medical aspects. In April 2012, Health Secretary Andrew Lansley announced the future creation of two units to treat patients with proton therapy. The announcement, just as in Spanish press, was criticized by some experts, who argued its high cost and the scarce evidence of its benefits in non-localized cancers such as brain or ocular cancer. However, the headlines highlighted the news as beneficial, especially for children with cancer: "The child-friendly cancer treatment coming to Britain" (*The Daily Mail*, 6 April, 2012), "America's 'posh radiotherapy' saved Lauren – and it's coming to Britain" (*The Mail on Sunday*, 22 December, 2013).

As previously stated, the Ashya King case quickly captured the attention of the press. References to PBT started appearing on August 31, 2014, after Ashya's brother uploaded a video to YouTube, in which the father explained that they were just trying to raise enough money to pay for PBT in a private centre in Prague, Czech Republic. Information on PBT was scarce before the case of Ashya King, but from that point onwards the media included information about it daily (Table 2).

Table 2. Proton beam therapy (PBT) coverage in English and Spanish press before and after Ashya King's case.



### 3.3. Protons and religious beliefs

The religious debate appeared at the same time as the news broke. The fact that the parents were Jehovah's Witnesses was highlighted during the first days the case went public, with a pivotal point on August 31, 2014. It was suggested the parents might have escaped to keep their son from receiving blood transfusions, necessary in radiotherapy and chemotherapy treatments. Once the parent's reasons to leave the hospital and bring the child to Prague were known, the fact did not resonate as much in the analysed press, but it did not disappear completely.

At first, most of the analysed newspapers in Spanish press attributed the escape of the parents from the hospital to their religious beliefs. This can be observed in headlines such as: "The quest for the transfusion-free treatment" (*La Razón*, 1/9/14). *El Mundo* also claimed in the September 3, 2014 op-ed that "Life is more important than parental rights" and asked: "Who has the last word on the treatment of a boy with terminal cancer? Do parents have the right to look for the solutions they consider more effective?" Even if this sort of arguments disappeared once the father stated in a press release that their religious beliefs were not above their son's life, references to their affiliation with Jehovah's Witnesses still appeared intermittently on the press.

Among British newspapers, first they highlighted the idea that the King family were Jehovah's Witnesses, in the same way than Spanish press. However, they quickly changed positions and started defending the cause of the parents, as is showed by headlines as the grandmother's plea when the parents were arrested in Spain: "Let them be with Ashya" (*The Sun*, 2/9/2014). The events were rather narrated as a story of good and bad guys, with the parents starting as kidnappers and religious fanatics and becoming loving parents who faced confronted the powerful NHS to save their son's life.

### 3.4. Who explains proton beam therapy?

PBT was mentioned (in the headline or the text) in 69.7 % of the 327 analysed items ( $N=228$ ;  $n=59$  in Spanish press and  $n=169$  in British press). Of them, 38.1 %, less than half ( $N=87$ ,  $n=22$  in Spanish press and  $n=65$  in British press) explained an aspect of the therapy in depth (what it consists on, its uses, recommended cases, its cost, where the centres are, pros and cons, etc.). That is, in Spanish press, 37.2 % of items referring to PBT (22 out of the 59 in which the therapy was mentioned) explained one or more aspects of the therapy. In British newspapers, 38.4 % (65 out of 169) items included some information on PBT in order to explain to the reader the technology. Newspapers resorted to radiotherapy experts for that, but most of the news items used the Proton Therapy Centre in Prague as their main source (Table 3). They highlighted the advantages of the technique, while radiotherapists and oncologists considered – as the British medical team – that the standard protocol would have been the best option in this case, although they recognized how promising the new technique was.

Table 3. Number of items explains proton beam therapy (PBT) by newspaper and sources of information. PTC correspond to Proton Therapy Center, in Prague. NHS correspond to National Health Service.

	Explains PBT			Sources of information						
	Yes	No	Total	PTC Staff	PTC website	Other oncology experts	Journalists/ Health editors	Ashya's parents/ Other cases' parents	NHS	Total
<i>El País</i>	1	7	8	-	-	1	-	-	-	1
<i>El Mundo</i>	3	13	16	-	-	1	2	-	-	3
<i>ABC</i>	6	15	21	4	-	1	1	-	-	6
<i>La Vanguardia</i>	8	14	22	6	1	1	-	-	-	8
<i>El Periódico</i>	-	4	6	-	-	-	-	-	-	-
<i>La Razón</i>	4	20	24	1	-	2	1	-	-	4
<b>Subtotal 1</b>	<b>22</b>	<b>73</b>	<b>97</b>	<b>11</b>	<b>1</b>	<b>6</b>	<b>4</b>	<b>0</b>	<b>0</b>	<b>22</b>
<i>The Times</i>	6	21	27	-	-	-	3	3	-	6
<i>The Guardian</i>	5	17	22	1	-	2	1	-	1	5
<i>The Daily Telegraph</i>	29	35	64	11	-	3	1	5	9	29
<i>The Daily Mail</i>	9	25	34	2	-	2	4	-	1	9
<i>The Daily Mirror</i>	7	34	41	-	1	-	4	-	2	7
<i>The Sun</i>	9	35	44	-	1	-	4	2	2	9
<b>Subtotal 2</b>	<b>65</b>	<b>167</b>	<b>232</b>	<b>14</b>	<b>2</b>	<b>7</b>	<b>17</b>	<b>10</b>	<b>15</b>	<b>65</b>
<b>TOTAL</b>	<b>87</b>	<b>240</b>	<b>329</b>	<b>25</b>	<b>3</b>	<b>13</b>	<b>21</b>	<b>10</b>	<b>15</b>	<b>87</b>

### 3.5. Comparative by countries

Press coverage of Ashya's case was much more intense in the UK ( $N=232$ ) than in Spain ( $N=95$ ). Information on the case was not only more abundant, but it also occupied a more prominent place: while it appeared on 25 covers from the studied British press sample, it was featured only twice on the covers of the Spanish sample. Likewise, as seen on the previous section, British press dedicated more news to talk about and explain PBT.

However, it was the Spanish press the one that gave more importance to the fact that the parents were Jehovah's Witnesses. Spanish newspapers highlighted this fact in 29 of the 95 analysed pieces (30.5 %) while British press mentioned it in 35 out of 232 (15 %).

When parents made explicit that their religious beliefs had not influenced their decision and that they only wanted to go abroad to get PBT for their child, Spanish newspapers looked for similar cases, with Spanish families. As in Spanish press, British newspapers looked for other examples. Almost all of them published the testimony of the mother of the first boy who received PBT treatment abroad:



“Proton treatment saved our son. Why did NHS deny Ashya?” (*The Telegraph*, 7/9/2014).

Concerning the high cost of the treatment, it enters the pages of the newspapers as soon as the parents revealed that they had travelled to Spain to sell a property and have enough money to pay for their son’s PBT. Although different amounts were discussed at first, the Proton Therapy Centre in Prague offered an approximate budget, around €81,000. It was finally discovered that the British health service would assume the cost of Ashya King’s proton beam treatment in Prague. But the cost of the treatment was not the only figure in the press. The cost to create the necessary facilities, which require large land extensions, was also discussed, as was the cost to maintain it and staff it with engineers and specialized workers.

By countries, UK dedicated a larger number of items to inform and argue about economic aspects related to PBT. While Spanish newspapers offered economic data in 24 out of 95 of the analysed sample (25.3 %), British press did so in 91 out of 232 pieces (39.2%).

#### 4. Discussion

Results of the current study show that British and Spanish press coverage of the Ashya King case contributed to public dissemination and knowledge about PBT. Despite the approach preferred by most of Spanish and British newspapers, closer to a human-interest story, a quarter of the articles explain what proton therapy is and how it works.

As seen in the results, before the King case, proton therapy was barely present in Spanish and British press. In fact, *La Razón* admits: “Until a couple of weeks ago, terms such as ‘medulloblastoma’ or ‘protontherapy’ were unknown for most of the population” (14/9/2014). Our study shows how, from Ashya King’s case, proton beam therapy became a common term and was used to demand said therapy.

By countries, British newspapers were more devoted to explaining the case details. This difference in media attention is to be expected because Ashya and his family were UK citizens and the issue concerned their public health system. Proximity and unexpectedness (Galtung and Ruge, 1981) were new values that quickly turned the case into an interesting topic for the media.

The fact that the parents were Jehovah’s witnesses helped to increase the case’s media impact, as the elevated number of pieces that mention it prove. Some studies (Song et al, 2014) show a reduction of the incidence of acute haematological toxicities with PBT and, therefore, less need for platelet and blood transfusions. Even if the father afterwards stated that their decision on the treatment had not been influenced by their religious beliefs, the truth is that several newspapers were still sceptic about this affirmation and kept on mentioning their affiliation with Jehovah’s Witnesses on the pieces they published on the case. Ashya’s father statement would be in accordance with some studies that show that younger Jehovah’s Witness patients or their parents are more likely to accept blood transfusion than older patients (Benson, 1995).

In the press of both countries, the most common sources of information to explain proton therapy were the professionals at the Centre for Proton Therapy in Prague. This biased a large part of the information in favour of the arguments of the centre. The case became then the perfect opportunity to promote the Proton Therapy Centre in Prague, as media uncritically replicated the statements of its team. They praised the technique and the centre once and again as being “the only centre of this type in Central and Eastern Europe”. Following their own words, the Czech centre was described by the press as “advanced” and proton therapy as an “exceptional” and “pioneering”. They also described it as the “best treatment”, which implies a positive evaluation compared to the “conventional” treatment chosen by the medical team of NHS.

In fact, the Prague clinic spokeswoman stated: “I am questioning the NHS. Why is it not sending more patients to Prague? They do send people for proton therapy but they send them to the United States — where they have good centres as well, of course, but unfortunately the NHS has to pay double or triple the price... They are sending people overseas for eight, ten, twelve hours, flying with a tumour in their head” (*The Times*, 24/3/15). In British newspapers, debate and criticism towards NHS were recurrent issues. The comparison of media coverage in both countries allows us to dig deeper on the cultural, economical and public health differences between them. In the Spanish context, the case was not used to bring up the need to offer PBT without leaving the country. In the UK, the public satisfaction with NHS went down from 70 % in 2010 to 60 % in 2015 (Appleby and Roberts, 2016). This ten-point decrease of public trust towards NHS might explain the larger presence of criticism towards the public health system on the British press.

The results of the study also show an under-representation of the NHS doctors. In fact, in September 6, 2014, *The Guardian* published the complaints of the medical team of Southampton hospital, who felt misrepresented by the press. Dr Peter Wilson, lead paediatrician at Southampton General Hospital, said: “Where we have been really misrepresented by the press and the family is where people have talked about a dying child”.

Favouring information from Prague’s clinic, press did not address aspects that might have added other aspects to the debate, such as the growth rate of tumours such as medulloblastoma, for which proton therapy offered few advantages (Hawkes, 2014).

*The Guardian* was one of the most nuanced British newspapers. On September 11, 2014, health editor Sarah Boseley stated: “Proton beam therapy is no magic bullet”. In November, the same newspaper published a report about a group of leading child cancer doctors who had written to NHS to express concern that other families would reject NHS advice after Ashya King’s case and demand treatment abroad.

The high cost of the facilities was definitely a relevant issue in the analysed sample, especially in British newspapers. The elevated cost of the treatment was the only highlighted disadvantage.

The controversy about PBT was not new. Already in 2007 the National Radiotherapy Advisory Group (NRAG) considered that there was sufficient literature “to justify the use of proton treatment for a number of indications [...] It is estimated that there is an immediate need for 400 patients per annum to receive

this treatment”. And recommended, in the long term, that “at least one modern proton treatment facility is set up in England” (National Radiotherapy Advisory Group, 2007: 30). In fact, the announcement of the health secretary on April 2012 responded to this request. However, some voices claimed then that there was no evidence with randomized clinical trials to prove that proton therapy would be beneficial to treat cancers other than ocular, brain and paediatric central nervous system cancers (Allen et al., 2012; Brada et al., 2007; Lewis, 2008). Others challenged the idea, like Goitein and Cox (2008), who defended that proton therapy was superior to X-ray therapy and that it was unethical to demand such trials. They defended that it was rather an economic issue: “Can anyone seriously believe that, if protons were cheaper than x-rays, there would be similar objections raised as to their immediate and widespread use?” (Goitein and Cox, 2008: 176).

Traditionally, experts decided their disputes in spaces that were only accessible to insiders, such as conferences or certain scientific journals. As Fleck (1979) described, the professional elite debated within their esoteric circle to later communicate consensual knowledge to a broader group of apprentices and initiates. Such knowledge would then reach the exoteric circle, formed by the press and public opinion. New technologies allow some members of society – who would have been part of the exoteric circle before – to acquire knowledge and become what Harry Collins considers “specialist experts”. For instance, “those with chronic diseases have knowledge about the treatment of those diseases that compares with or even exceeds that of their doctors” (Collins, 2014: 64). Their knowledge is based on their own experience, on the information exchange with other patients and medical professionals, and on reading professional journals and technical material on the Internet.

In this case, the Kings obtained information, decided to go for PBT and forced the situation to achieve what they considered was a better treatment for their child. Press coverage, after the first moment, helped spread and, very often, validate the parents’ idea that PBT was a better and more innovative therapy. It might have been interesting to have a more profound debate on PBT and conventional radiotherapy; one that explored, for instance, the ideal cases for the treatment, what meta-analysis and studies current protocols for childhood medulloblastoma are based on, what happens with other types of cancer such as prostate cancer, and many other unaddressed topics. PBT facilities are the most expensive medical devices ever employed for the routine delivery of health care (Mills and Schulz, 2015). It seems logical that cancer patients would relate this therapy with a favourable outcome. Without adequate information, people might think that a newer, more expensive therapy is always better.

## 5. Conclusion

This study has encountered some limitations. The elaboration of the sample by means of online academic newspaper databases might have left out some elements of interest for the research. This could apply both to the period before Ashya’s case and after it. Nevertheless, this research shows some remarkable findings. Ashya King’s case was successful in bringing proton beam therapy to the public trough

the media. Furthermore, the demand of the King family became a collective need, especially in UK. The NHS not only assumed the cost of the boy's treatment in Prague, but also publicly announced the construction of two PBT centres in the UK, which should be ready for patients in the near future.

The analysis of press coverage shows how the religious beliefs of the protagonists were exploited to raise public interest, which caused great media impact; sensationalism and inaccuracy were not uncommon during this period. Likewise, we can observe how the prominence of one source in particular – the centre that offers PBT – increased the public pressure for Ashya to obtain said treatment.

It is also observed the necessity to improve the medical information when a case like this appears in public opinion. The patient, as well as the society, always asks for the latest technology for their treatment. As we have observed, this raises a number of challenges: the need to work with protocols that guarantee access to the best treatment that has proved to be effective, the right to equality in the administration of treatment, economic extra charges, or medical overtreatment, to name a few.

Therefore, the findings of this research have implications for the study of the communication of new medical technologies. As we showed, diffusion is not vertical or linear; people become communicators and abandon their passive receiver role. It also provides new data about how technology and medical controversy reaches different audiences. This case shows that, while the sphere of experts keeps debating about the possible benefits of extending the therapy to a higher number of patients, the public sphere has already decided to adopt the technology.

## 6. References

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